

APPENDIX A

Entered: File T _

Date: / /

JRB ASSOCIATES
JACKSON LONGITUDINAL STUDY
QUALITY OF LIFE SURVEY (INTERVIEW PORTION)*

To be completed prior to field use:

Control #: _____

Sex: M F

Age: _____

Consent received (date of signed consent letter) _____

Oral Consent Form (read or signed to respondent):

Hello, I am _____. I'm working on a project to learn how people who are moving to new homes feel about what's happening. What is your name? _____ (Enter # only, not name.)

I am here to ask you some questions about your life and what you do. No one but us and the people working on this project will ever find out what you say. I do not work for the State of New Mexico. What you say will be secret and confidential. I think it is important to find out about you and your feelings. If you do not want to talk to me, you do not have to. You can stop any time. Will you talk with me (us)?

Class Member Consents:

YES

NO

INTERVIEW DATE: _____**INTERVIEW START TIME:**Survey (circle): T₀ (Pretest) T₁ T₂ T₃ T₄ T₅

Interview location (residence): D house; D apartment; other (describe) _____

Has resident moved since transition to community? ? Yes; how many times? ____ . D No.

Has resident moved since last JLS visit? D Yes;; ? No. Street address and phone if different from our records: _____

Reasons for relocating: D mover preference; ? social conflict with peers or staff; D problems in providing necessary services (move initiated by provider or state); ? other (describe) _____

Type of arrangement: ? Supported Living; D Other (describe) _____. Number of residents: ____

Staff/resident ratio - day: ____ : ____; night: ____ : ____; weekend: ____ : _____. Support level: D 24 hour awake; D 24 hour sleep-in; ? less than 24 hour.

☐ ☐ ☐

Name of client's helper/proxy, if present: _____. Status: day night other: _____

ANSWERED BY: ? Proxy 100% ? Proxy>50% D Client>50% ☐ Client 100%

Length of time helper or staff person has been assigned to client (Years and Months): _____

QUALITY OF LIVING CONDITIONS:

Q1 Do you like living here? A LOT SOME NOT MUCH DK/NA

1.1 What do you like about it?

1.2 What don't you like about it?

Q2 Have you lived somewhere else before? Q2.1 YES NO Not
If yes, *how* did you like living there?

A lot Some much DK/NA

Q3 If you could live anywhere you want, where would you live? *[If
mover would stay here, skip to Q4.J 3.1* What would be
better about living there?

3.2 What might not be so good about it?

Q4 How comfortable are you with your current home? D
SATISFIED D SOMEWHAT SATISFIED D
DISSATISFIED

WHY?

FEELINGS ABOUT PROVIDERS/PEOPLE "IN CHARGE"

Q5 Who do you like? [First names. Does mover identify helper/proxy? D Yes. ? No.]

Q5.1 Do you like the people here who are supposed to help you?

ALL OF THEM MOST OF THEM NONE OF THEM DK/NA

- 5.2 Tell me what you like about them. Do they *[check all that apply and note additional reasons mentioned.]* [Note mover's perceptions about what staff members mean to their lives. To be used for case studies.]

? listen to you?

D make you feel happy?

D understand what you need?

D What else?

- 5.3 Does anyone here hurt you? YES NO DK/NA

[If yes] Who is that? [Check whether staff or peer.] O staff O peer

[If yes] What do they do to hurt you? C "feelings " O physical

Are there O JUST ONE O A FEW ? LOTS of people who make you feel this way?

QUALITY OF SOCIAL RELATIONS/INTERACTIONS

- Q6 Do you have a special friend here?

? I DO

? MAYBE

D I DON'T

- 6.1 *[If yes] Who is that? [First name. Check whether staff or peer.]*

O staff O peer

6.1 A In what way is this person "special" to you?

- 6.2 Who else are your friends here? *[Record **number** of other friends.]*

- 6.3 How did you meet your friends? *[Residence or "outside "-- work or elsewhere]*

- Q7 What do you like to do with your friends? *[Record activities; number of discrete activities.]*

- Q8 Do friends visit you? YES NO

- 8.1 When can friends visit you?

D WHENEVER I WANT

D ANY DAY, AS LONG AS STAFF OR SOMEONE ELSE APPROVES

D ONLY ON CERTAIN DAYS

Q9 How do spend your time when you are not at work, school or training, or doing chores?
[Record discrete activities.]

Q10 Do you have family? YES NO DK/NA

10.1 Does your family visit you? YES NO DK/NA

10.2 Who comes to visit you? *[List family visitors.]* Number of family visitors listed:

10.3 How often do they visit you? *[Note which ones visit how often.]*

A LOT SOMETIMES SELDOM

10.4 Do you visit your family? YES NO DK/NA

10.5 How often do you visit them? A LOT SOMETIMES SELDOM

Q11 Are you happy?

- ☐ USUALLY HAPPY
- ☐ SOMETIMES HAPPY
- ☐ NOT HAPPY

Q12 Are you sad?

- ☐ USUALLY SAD
- ☐ SOMETIMES SAD
- ☐ NOT SAD

Q13 Are you afraid?

- ☐ USUALLY AFRAID
- ☐ SOMETIMES AFRAID
- ☐ NOT AFRAID

Q13.1 Are you angry?

- ☐ USUALLY ANGRY
- ☐ SOMETIMES ANGRY
- ☐ NOT ANGRY

Q14 What do you do for fun?

14.1 Do you... [Frequency]

- ☐ Play sports?
- ☐ Go swimming?
- ☐ Dance?
- ☐ Attend Fiestas?
- ☐ Attend Feast Days?
- ☐ Go bowling?
- ☐ Go on walks?
- ☐ Watch TV?
- ☐ Play computer games?
- ☐ What else?

14.2 How often do you do these things [Code for each activity checked using codes below]?

(1)Every day

(2) Once a week

(3)Less than once a week

PRIVACY/EMPOWERMENT/CHOICE MAKING

Now I'd like to ask you about how you spend your day.

Q15 I guess you get out of bed in the morning every day. Is that right? [Not coded; lead in to following.]

15.1 Who picks what time you get up in the morning?

- ☐ I DO.
- ☐ I DO WITH STAFF OR SOMEONE ELSE'S HELP.
- ☐ STAFF OR SOMEONE ELSE DOES.

OMIT ~~15.2 What are the things that you do every day? [List.]~~

~~☐ Routine list only.~~

15.3 Who says what things you will do?

- ☐ I DO.
- ☐ I DO WITH STAFF OR SOMEONE ELSE'S HELP.
- ☐ STAFF OR SOMEONE ELSE DOES.

15.4 Can you decide not to do some things if you don't want to?

- ☐ YES, I CAN.
- ☐ YES, I CAN, WITH STAFF OR SOMEONE ELSE'S HELP.
- ☐ NO, I CAN'T.

Q16 Do you have a key to your home or room?

- ☐ YES, I HAVE A KEY AND USE IT AS I WISH
- ☐ YES, I HAVE A KEY, BUT ONLY USE IT WITH HELP.
- ☐ NO, I DON'T.

Q16.1 Who else has a key?

Q16.2 Is this okay? YES NO DK/NA

Q17 Are there times you want to be alone?

- ☐ FREQUENTLY
- ☐ OCCASIONALLY
- ☐ SELDOM

17.1 Can you be alone when you want to?

- ☐ YES, I CAN.
- ☐ YES, I CAN, WITH SOMEONE ELSE'S APPROVAL.
- ☐ NO, I CAN'T.

17.2 Where do you go when you want to be alone?

Q18 What stuff in your room or your home is yours? *[List.]* [Note relative quantity of personal property and indicate mover's sense of ownership and "connectedness" with personal property in her/his environment.]

18.1 How did you get these things?

[Were they bought with the person's money? O Yes O No]

18.2 Who bought these things?

- ☐ I DID.
- ☐ I DID, WITH STAFF OR SOMEONE ELSE'S HELP.
- ☐ STAFF OR SOMEONE ELSE DID.

- Q19 Who picks the clothes you wear?
- 19.1 How did you get these clothes?
[Were they bought with the person's money? ☐ Yes ☐ No]
- 19.2 Who bought these things?
- ☐ I DID.
 - ☐ I DID, WITH STAFF OR SOMEONE ELSE'S HELP.
 - ☐ STAFF OR SOMEONE ELSE DID.
- Q20 What foods do you like best? *[not coded]*
- 20.1 Who buys your food?
- ☐ I DO.
 - ☐ I DO, WITH STAFF OR SOMEONE ELSE'S HELP.
 - ☐ STAFF OR SOMEONE ELSE DOES.
- 20.2 Can you get the food you like best? YES NO
- Q21 Do you have your own money? YES NO
- 21.1 Do you keep your own money? YES NO
- 21.2 How do you get your money? *[✓ all that apply.]*
- ☐ I HAVE A JOB
 - ☐ I ATTEND A TRAINING PROGRAM
 - ☐ I GET MONEY FROM MY FAMILY
 - ☐ I ASK SOMEONE FOR IT
 - ☐ FROM THE STATE
 - ☐ OTHER
- Q22 What do you spend your money on? (What do you buy?) *[Include rent, utilities, etc. if mover mentions them.]*
- 22.1 Can you buy things you want?
- ☐ YES I CAN
 - ☐ YES, IF I ASK
 - ☐ NO, I CANNOT
- Q23 Do you go to school, training, or work? ☐ YES ☐ NO
- If yes, which one(s): _____ *[Elaborate as much as possible.]*

23.1	Who picked it?		
	<input type="checkbox"/> I PICKED IT.		
	<input type="checkbox"/> I PICKED IT, WITH STAFF OR SOMEONE ELSE'S HELP.		
	<input type="checkbox"/> STAFF OR SOMEONE ELSE PICKED IT FOR ME.		
23.2	Why did you (they) pick it?		
23.3	Do you like it?	YES	NO
23.4	What do you like about it?		
23.5	What don't you like about it?		
23.6	How do you get to work, school or training?		
	<input type="checkbox"/> BY MYSELF		
	<input type="checkbox"/> I GO WITH A GROUP OF PEOPLE		
	<input type="checkbox"/> SOMEONE TAKES ME		
Q24	Can you see a doctor when you need to?	YES	NO
24.2	Can you see the doctor you like?	YES	NO
OMIT 24.1	Who picked your doctor?		
	<input type="checkbox"/> I DID.		
	<input type="checkbox"/> I DID, WITH STAFF OR SOMEONE ELSE'S HELP.		
	<input type="checkbox"/> STAFF OR SOMEONE ELSE DID.		
24.3	How do you go to see your doctor?		
	<input type="checkbox"/> BY MYSELF		
	<input type="checkbox"/> SOMEONE TAKES ME; BUT I SEE THEM MYSELF.		
	<input type="checkbox"/> SOMEONE TAKES ME AND STAYS WITH ME.		
24.4	Does your doctor listen to you?		
	<input type="checkbox"/> ALWAYS.		
	<input type="checkbox"/> SOMETIMES.		
	<input type="checkbox"/> NEVER.		

- 24.5 Does your doctor help you with what is wrong?
- ☐ ALWAYS.
- ☐ SOMETIMES.
- ☐ NEVER.

Do you go to any groups or clubs, like ...

PEOPLE FIRST	YES	NO	NO
SELF-ADVOCACY GROUP	YES	NO	
ART CLUB	YES	NO	
SPECIAL OLYMPICS	YES	NO	
COMMUNITY GROUP	YES	NO	
CONSUMER GROUP	YES	NO	
DANCE CLUB	YES	NO	
CHURCH GROUP	YES	NO	
OTHER GROUP:			

Q25

25.1 How do you get there?

- ☐ BY MYSELF
- ☐ I GO WITH A GROUP OF PEOPLE
- ☐ SOMEONE TAKES ME

Q26 Is there anything you would like to tell me about? YES NO DK/NA

[If yes, note mover's comments or helper's comments as proxy for how mover feels. Record other comments about mover (e.g., mover's behavior) on observation instrument as appropriate. Continue on reverse.]

Thank you, _____, for all your assistance. I enjoyed visiting with you and appreciate your talking with me.

Time INTERVIEW ended:

APPENDIX A

INTERVIEW INSTRUMENT, Page 10

[Use this page to continue responses to Interview Instrument Q26 and Contextual Observations.]

Q26. [continuation of responses]

[Continuation of Contextual Observations. Number consecutively following #23.]

JRB ASSOCIATES JACKSON
LONGITUDINAL STUDY
CONTEXTUAL OBSERVATIONS AS INDICATORS OF QUALITY OF LIFE AND
QUALITY OF CARE

CONTROL #_____ Observation visit date/time if different from interview visit

Staff (in addition to helper) consulted during observation visit

PHYSICAL SETTING:

These observations relate to the location of the residence safety and security maintenance access to transportation and community based resources quality of living environment and nature of the individual's home or room furnishings

- 1 Is the home in a safe neighborhood (in either city or rural environment)? *[Please observe and select appropriate response category]*

VERY SAFE

SAFE

UNSAFE

OTHER OBSERVATIONS

- 2 Is the home maintained?

WELL MAINTAINED

MAINTAINED

UNMAINTAINED

OTHER OBSERVATIONS

- 3 Is the home a barrier free environment for the individual?

NO BARRIERS

SOMEWHAT ACCESSIBLE

NOT ACCESSIBLE

OTHER OBSERVATIONS

4. What is the condition of the furnishings?

EXCELLENT

GOOD

MARGINAL

POOR

OTHER OBSERVATIONS:

5. Is the residence large enough to accommodate those living in it? Space is:

AMPLE

ADEQUATE

MARGINAL

UNACCEPTABLE

OTHER OBSERVATIONS:

Observe the following physical characteristics and note:

6.1 windows/light AMPLE ADEQUATE MARGINAL UNACCEPTABLE

6.2 smell/ventilation AMPLE ADEQUATE MARGINAL UNACCEPTABLE

6.3 colors/decoration AMPLE ADEQUATE MARGINAL UNACCEPTABLE

6.4 temperature COMFORTABLE UNCOMFORTABLE

NOTES:

The food tastes good, looks good and healthful. *[If you have the opportunity to eat at the residence please do so. If not, look at menus, ask permission to examine refrigerator, freezer, cupboards, etc.]*

ACCEPTABLE

MARGINAL

UNACCEPTABLE

OTHER OBSERVATIONS:

8. Is the home secure?

VERY SECURE

ACCEPTABLY SECURE

INSECURE

OTHER OBSERVATIONS:

9. There is easy physical access to the community. *[Ask the staff; observe signs of community interaction and/or involvement.]*

EXCELLENT

ACCEPTABLE

MARGINAL

UNACCEPTABLE

OTHER OBSERVATIONS:

STAFF AND QUALITY OF CARE:

These observations/questions are intended to provide data about the staffs level of competence; friendliness; attitude and behavior toward the residents.

- * 10. Ask the staff members closest to the Jackson client where they were trained and determine their prior experience with the developmental disability population. *[You may do this prior to meeting the mover, or at the end of the visit, whenever you ask Q. 22. This question provides context only; we are not assessing staff competence!]*

Training: On-the job [months/years] _____

Formal education [months/years]_

Experience: [years] _____

- 10.1 Staff members observed speak in an assertive, respectful tone in dealing with clients and each other.

ALWAYS

USUALLY

SELDOM OR NEVER

OTHER OBSERVATIONS:

- 10.2 Verbal communication is congruent with their body language.

ALWAYS

USUALLY

SELDOM OR NEVER

OTHER OBSERVATIONS:

11. Staff members are clean and have no signs of illness.

ACCEPTABLE

MARGINAL

UNACCEPTABLE

OTHER OBSERVATIONS:

12. Staff members are knowledgeable about the health and medical needs of the individuals living there.

EXCELLENT

ACCEPTABLE

UNACCEPTABLE

OTHER OBSERVATIONS:

REGARD FOR THE INDIVIDUAL; INDIVIDUAL GROWTH

These observations examine the acceptance of individual differences; the importance of self-worth; opportunities to make choices; and social interactions.

13. Individual looks good in her or his clothing. *[Observe individual; ask permission to examine their wardrobe.]*

ACCEPTABLE

MARGINAL

UNACCEPTABLE

OTHER OBSERVATIONS:

14. Individual has a clean appearance. *[Observe individual]*

ACCEPTABLE

MARGINAL

UNACCEPTABLE

OTHER OBSERVATIONS:

15. Individual has her/his own private space and property. *[Observe.]*

EXCELLENT

ACCEPTABLE

MARGINAL

UNACCEPTABLE

OTHER OBSERVATIONS:

16. Individual is given opportunity to make choices related to his/her own life. *[Observe the degree choice-making opportunities are offered to the individual]*

EXCELLENT

ACCEPTABLE

MARGINAL

UNACCEPTABLE

OTHER OBSERVATIONS:

- 17 Friendships and social relations are encouraged and supported *[Ask staff members observe pictures of friends observe interactions at the residence]*
- EXCELLENT ACCEPTABLE MARGINAL UNACCEPTABLE
- OTHER OBSERVATIONS

PERSONAL GROWTH

These observations examine the opportunities for individual growth and development; opportunities to have fun take classes enjoy cultural events go on trips and take individual risks

- 18 The individual has necessary adaptive equipment to move around their home and community *[Ask individual ask staff and observe the individual s equipment]*
- EXCELLENT ACCEPTABLE MARGINAL UNACCEPTABLE
- OTHER OBSERVATIONS

- 19 The individual is given information (verbally or prompted) to encourage personal well being (exercise diet communication) *[Observe and ask staff]*
- EXCELLENT ACCEPTABLE MARGINAL UNACCEPTABLE
- OTHER OBSERVATIONS

SAFETY

These observations examine the safety of residence and the surrounding area the safety procedures of the residence and access to medical care

- 20 Individual gets regular medical attention *[Ask staff and observe signs like a log of individual s medical history and record of health care]*
- ACCEPTABLE MARGINAL UNACCEPTABLE
- OTHER OBSERVATIONS

21. Individual gets regular scheduled dental care. *[Ask staff, and observe.]*

ACCEPTABLE

MARGINAL

UNACCEPTABLE

OTHER OBSERVATIONS:

*22. Plans/procedures are in place for dealing with the following: *[Ask staff, and observe. (Note: N/A is acceptable for those living in non-licensed supported living arrangements, such as parents' home, depending on the circumstances.)]*

22.1 fires and medical emergencies

ACCEPTABLE

MARGINAL

UNACCEPTABLE

22.2 reporting special incidents

ACCEPTABLE

MARGINAL

UNACCEPTABLE

22.3 abuse and neglect prevention and reporting

ACCEPTABLE

MARGINAL

UNACCEPTABLE

22.4 Individual Program Plans (IPP)

ACCEPTABLE

MARGINAL

UNACCEPTABLE

OTHER OBSERVATIONS *(Number consecutively; continue on p. 10 of Interview Instrument if additional space is needed.)*

23.

Time visit ended: _____ Elapsed time (int. + obs.): _____

Did visit include opportunity to observe meal preparation? Y N Were you present during mealtime? Y

Was it necessary to phone staff to obtain additional data after the visit? Y N Which questions (#)?

